

Primary care for persons with intellectual disabilities: Issue for practice

**Owen Doody, Maria E Bailey and Rosemary Lyons,
Department of Nursing and Midwifery, University of Limerick.**

In tandem with a growing population, Ireland is further witness to a change in the demography of persons with intellectual disability. The Annual Report of The National Intellectual Disability Database highlights in particular that people with intellectual disability are surviving into old age and that they are requiring services appropriate to their age group (Kelly et al., 2008). The trend for institutional care has been outmoded (Sheerin and McConkey, 2008; McConkey et al., 2005) with more persons with an intellectual disability living in the community. In 2008 a total of 26, 023 people were registered on the National Intellectual Disability Database (Kelly et al., 2008). From this database it is evident that there were more males (56.6%) than females (43.4%), with the highest proportion of both males and females diagnosed as having a moderate level of intellectual disability. Of these individuals, 25,433 were in receipt of services, 16,708 (64.2%) were living at home with family/carer and only 8290 (31.9%) were living in full time residential services. These residential services mainly included community group homes and residential centres while 950 individuals (3.7%) lived independently or semi independently (Kelly et al., 2008).

This move to the community is based on the principle of normalisation (Wolfensberger 1972) who later reconceptualised normalisation and proposing to replace the term with 'social role valorisation' reflecting his concern that certain groups in society such as persons with intellectual disability were perceived as having devalued social roles (Wolfensberger 1983). He argued that devalued groups tend to be cast into negative roles and called for a move away from segregation, special treatment and institutionalisation. Social role valorisation embodies the ideal that persons with an intellectual disability should be integrated into society, and offered the opportunity to access generic services which serve the general public. In tandem with the increased life expectancy and prevalence of persons living in the community it follows that all healthcare workers of the future will be required at some level to engage and support persons with an intellectual disability and their family/carer(s).

As the first point of contact, primary care is considered the appropriate setting to meet 90-95% of all health needs (Department of Health and Children 2001) and is founded upon the core principles of equity, person centred care, quality and accountability. However Ziviani et al (2004) and more recently Michael (2008) identified that adults and children with intellectual disability experience significantly greater difficulties than others in accessing assessment and treatment for general health problems that are not related to their disability. International researchers Cummins and Lua (2004); Lennox et al (2001); Powrie (2001); Whittaker and McIntosh (2000) have indicated that there are significant shortcomings in the health of adults with an intellectual disability and that their healthcare needs are being overlooked in the community. For example, persons with intellectual disability are known to have greater health needs and yet they are less likely to visit general practitioners or avail of preventative services (National Health Service Executive, 1998). As a result of communication difficulties, persons with intellectual disability may not describe symptoms to their general practitioners until disease has advanced and moreover these individuals cannot always be expected to arrange their own preventative care (Iacono et al., 2003; Turner and Moss, 1996). Disease progression caused by delayed presentation for healthcare screening will mean that many persons with intellectual disability will require earlier nursing intervention and support (Powrie, 2003). In Ireland, the Department of Health and Children (2001) argue that if primary care services and resources are available to all, this would reduce the potential for disparities in health, thereby increasing the population's opportunities to live healthy productive lives (Schoen et al., 2004).

Issues in supporting the healthcare needs of persons with intellectual disability living in the community appear to be dual focused around the client themselves and/or the process of accessing healthcare. While primary care teams rely strongly on an individual's ability to recognise and report symptoms of ill health (Turner and Moss, 1996), this poses problems for persons with intellectual disability and their family/carers. Ziviani et al (2004) notes that clients may not have sufficient skill or knowledge to aid in the consultation process. When persons have difficulty articulating their own individual health needs, appropriate medical assessment is challenging (Ziviani et al., 2004). In the community general practitioners within primary care teams have expressed concerns with communication difficulties which influence their ability to adequately diagnose, manage and inform clients/relative/carers (Melville et al., 2005; Ziviani et al., 2004). For the family/carer(s) of persons with

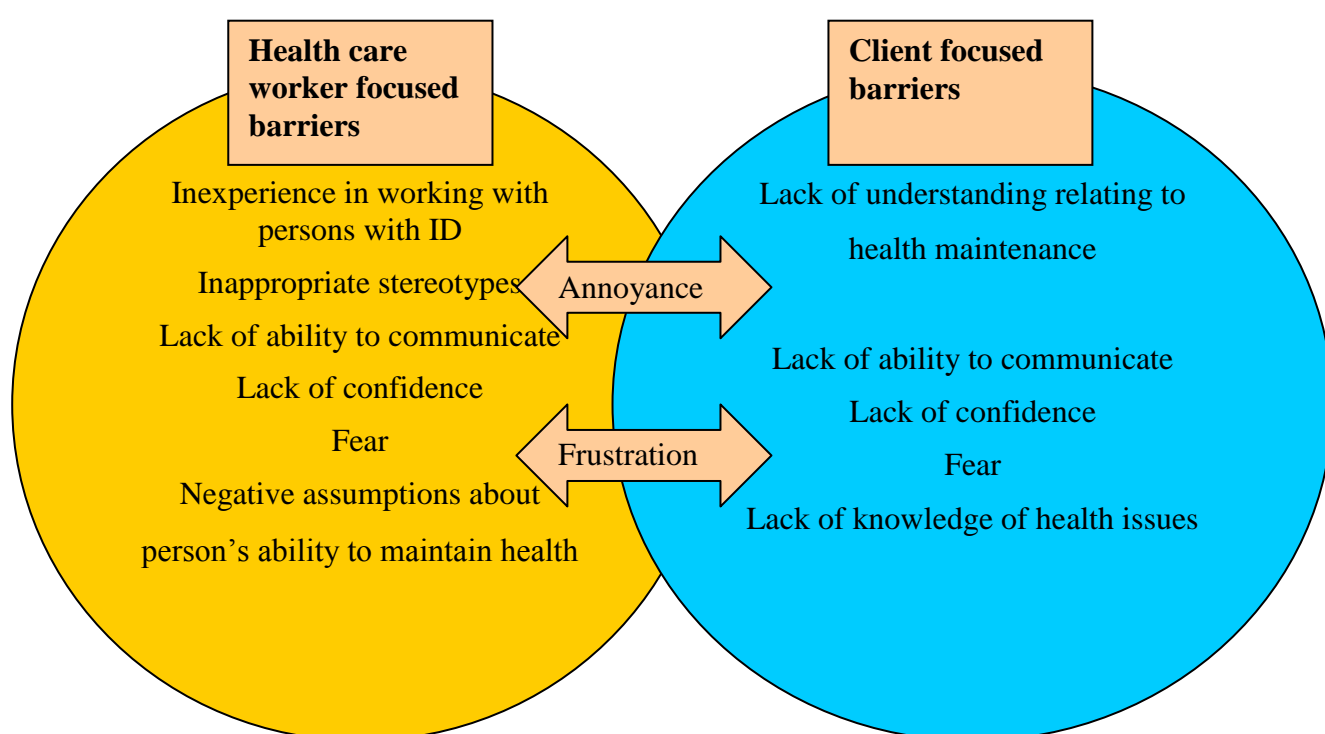
intellectual disability, interaction with the primary care team frequently commences following the birth/diagnosis of a child with an intellectual disability. The primary desire of parents is to care for their child with intellectual disability at home (Llewellyn et al., 2005). This places increased pressure on families in their caring role (McConkey, 2005). The older or more physically dependent the child, the more parents struggle to care for their child (Llewellyn et al., 2005; McConkey, 2005) with the parent's capacity to continue in a caring role diminishing over time (National Intellectual Disability Database, 2006).

The impact of caring is multifaceted and encompasses financial, social and practical aspects of the lives of families (Hartrey and Wells, 2003; Redmond and Richardson, 2003). Caring for a person with high support needs leaves parents exhausted emotionally and physically (Lecavalier et al., 2006; Mase et al., 2003), experiencing cycles of anxiety, frustration, loneliness, stress and burnout (Jeon et al., 2005). Caring for a person with intellectual disability has a cascading effect on the health of the family and the needs of both the family and person with intellectual disability should be met in order to deliver a quality service. Though needs vary, all families will require individual and practical support (Forde et al., 2004; MacDonald and Callery, 2004) and the availability of such support provides an invaluable service to parents (Jeon et al., 2005; Miller, 2002). Hartrey and Wells (2003) argue that families require services that are comprehensive, accessible and available in an emergency.

Melville et al (2005); Voelker (2002); Beange and Lennox (1998) note that an inadequate knowledge of services and resources, coupled with little time for examination and consultation were issues identified as barriers to the provision of adequate care for persons with intellectual disability. Similarly ascertaining whether the person with intellectual disability is able to give consent for medical procedures or screening such as cervical smears, breast examination or testicular examinations may also present problems due to a lack of understanding (Powrie, 2003). It is interesting to note that similar difficulties may also be experienced by other healthcare workers as illustrated in Figure 1, the imbalance depicted in this figure suggests that the cause and therefore the 'cure' lies largely within the domain of the healthcare worker. The figure further suggests that many of these barriers are shared by both healthcare worker and the client with an intellectual disability.

This is of concern given that one group has a professional role in caring and supporting the other. It is hardly surprising therefore that persons with intellectual disability report frustration and annoyance when they cannot adequately communicate to i.e general practitioners or when overlooked in the communication exchange (Melville et al., 2005; Ziviani et al., 2004). As a result of this poor communication, which leads to frustration on the part of the person with intellectual disability, there may be an expression of the need for understanding, which can often be perceived as inappropriate behaviour and negatively affects the consultation process (Doyle, 2006; Ouellette-Kuntz, 2005).

Figure 1: Healthcare worker and Client focused barriers to primary care



Healthcare workers have a key role in addressing the health needs of persons with intellectual disability ensuring equal access to all aspects of health promotion services, including health education and health surveillance with appropriate additional support as required meeting individual needs (Melville et al., 2005; Barr et al., 1999). However, contrary to the best intentions health promotion can unconsciously create health inequalities (Leeder and Dominello, 2005; Department of Health, 1999) with the result that those in greatest need of health promotion are most missing out. This is an extensive challenge to the primary care system as health promotion presently is delivered for the general public as

a whole; and has the potential to create problems in relation to comprehension and understanding of persons with intellectual disability and only further widens the gap of an inequitable rather than an equitable service. As health promotion focuses on the total population and its environment, careful attention is essential in order not to overlook minority/vulnerable groups (Leeder and Dominello, 2005). In essence health promotion within primary care may present numerous obstacles which relate to the nature of available information, the availability of time, the availability of adequate equipment and the knowledge, skills and attitudes of staff (Rimmer and Braddock, 2002; Barr et al., 1999; Band, 1998).

Although healthcare workers have identified that they feel they ought to strive to meet the health and social needs of persons with intellectual disability they have also indicated that they perceive themselves to be ill equipped to provide for this diverse group, (Ziviani et al., 2004). Furthermore, and not altogether surprisingly, these healthcare workers argued that persons with intellectual disability are best suited to be managed outside of primary care services (Powrie, 2003; Bollard, 2002). This raises the need for a professional experienced nurse from intellectual disability to liaise between the family and the primary care team. In Ireland it may be argued that the inclusion of RNID's (Registered Nurse Intellectual Disability) in Primary Care Teams would aid communication skills between all parties and reduce the health disparities of persons with an intellectual disability.

Now in the 50th year of regulated existence in Ireland the role of the RNID is specialised and unique from other disciplines of nursing with their education and training based upon the philosophy that each person with an intellectual disability has *'a right and a need to live within the community like other persons and they have a right to receive those services necessary to meet their specialised and changing needs'* (An Bord Altranais, 2010, p.17). The RNID is equipped with an in-depth knowledge and skill in the provision of nursing care and management for a diverse range of disabilities together with experience of client behaviours and client/nurse relationships of persons with intellectual disability. The nurse provides a comprehensive healthcare service responding effectively to the needs of persons with intellectual disability not just in terms of treatment of healthcare problems but also by addressing overall wellbeing and understanding and respecting the individual and their family (Lindsey, 2002). The inclusion of RNID expertise may also provide a strategy to

enhance the consultation process and reinforce screening a view expressed in the United Kingdom by Powrie (2003). Powrie argued for the inclusion of the registered nurse in intellectual disability within the primary care team or network based according to the population statistics. Such an initiative is worthy of further consideration in the Irish context.

Quality healthcare is a social right that every citizen should experience. All citizens should be assured that care is guaranteed and appropriate in their times of vulnerability. A socially inclusive society takes responsibility for and reduces the social consequences of having intellectual disability. However, this can only be achieved by all services taking responsibility for and supporting the individual to be as independent as possible in the community (Powrie, 2003; Mc Conkey, 2002; Duvdevany, 2000). It must be emphasised that unmet or misdiagnosed health needs for the person with intellectual disability often results in carers becoming socially isolated and potentially vulnerable when the pressure on the family of caring for the person with intellectual disability becomes overwhelming (Powrie, 2003; Llewellyn and McConnell, 2002). As primary care is founded on the core principles of equity, person centred care, quality and accountability; deliver an equitable multidisciplinary model of care is dependent upon qualified competent and flexible staff reflecting in order to meet the changing demands of the health system (Department of Health and Children, 2004). While this is a laudable and a positive approach to a significant health challenge, it may be argued that current health strategy fails to address the needs of existing healthcare worker in developing individual knowledge, skills and attitudes relating to caring and supporting persons with intellectual disability. Responding to the health care needs of persons with intellectual disability will always remain a challenge as communication barriers and ethical dilemmas making it difficult to fully implement all health provisions (Ouellette-Kuntz, 2005; Ziviani et al., 2004; Powrie, 2003).

Consequently the inclusion of relevant staff, persons with intellectual disability and their families should be an integral component of the planning, development and delivery of healthcare services and education programmes. Such initiatives should be tailored to meet the needs of persons with intellectual disability with the aim of providing accessible information and improving the client/healthcare worker interaction (Cumella and Martin, 2004; Iacono and Davis, 2003; Turner and Moss, 1996). If we truly support the philosophy

of healthcare for all we need to live this through our endeavours to create a tapestry of education and support for the client the family and healthcare worker. In order to inform our practice further research in Ireland pertaining to the utilisation of general healthcare services for persons with an intellectual disability is required.

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